

WORDS

The Newsletter of the Worster-Drought Syndrome Support Group

ISSUE 14

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Letter from the Chairman

Welcome to issue 14 of our newsletter WORDS.

Before we go any further I must personally thank Paul Butt for doing a sterling job in laying out our newsletter in the past, but due to his university commitments he has had to step aside and let someone else have a go. For the time being I have stepped into the breach and as such you will notice a slightly different look to previous issues. If, however, anyone else out there has the time and would like to help with the production of our newsletter, please get in touch. Your help would be greatly appreciated.

We are all beginning to look forward to our next Family Fun Day, this time at London Zoo on Saturday 12th June.

Our last visit to the Zoo 2 years ago was such a great success we decided to go there again, this time coinciding with their own special needs day. Again we look forward to a question and answer session and indeed our annual AGM. Details of these can be found later in this newsletter. Once more I must send out a big thank you, this time to Monique Lauder and her team for putting together this years Family Fun Day, again funded by Children No1 Foundation.

I look forward to meeting you all at the Zoo and I promise to keep the AGM as short as possible so we can get on with the fun.

Gavin Leech

Formal Notification of Annual General Meeting

Our 2004 AGM will take place during the Family Fun Day at London Zoo on Saturday 12th of June. All committee positions will be for re-election and anyone who wishes to stand for a committee position must notify our secretary, Hayley Herman as soon as possible. You can find her details at the end of this newsletter.

Family Fun Day

This year's family fun day is to be on Saturday 12th June at London Zoo.

Hopefully everyone will have received all the information and is able to make it.

On arrival we will be meeting at the Huxley centre which approximately 100 yards on the left after the main gate.

The Log Cabin who are a specialist organisation in caring for children with special needs are providing us with crèche facilities again for the under 3's, and they will be escorting children over 3 around the zoo. However, due to it's popularity, this has been fully subscribed

Our Annual general meeting will follow and there will be presentations by Andrew Lysley and Rachel Moore from the ACE centre that are experts in research and development and speech and language therapy.

Professor Neville From Great Ormond Street and Katie Price from the Wolfson Centre and Prof. R. Guerrini are also attending and will complete our panel for questions and answers.

Once again this event has been kindly sponsored by the children's No.1 foundation and we are extremely grateful for all their support.

For anyone who hasn't received any information about the event and will like to come please contact Monique Lauder on 0208 428 6706 or by email monique.lauder@btopenworld.com

For everyone else, we look forward to seeing you all on the day.

Fundraising

We still need to raise funds so further work can be done towards Worster Drought Syndrome. Whether it is towards proposed research or information packs for new families we have set up a fundraising team who can help you with any questions regarding this. You can find the contact details on the last page of this newsletter.

Great North Runners raise £912.00 for WDS-SG



Massive thanks to friends Selina Cross, Jimmy Murray and his wife who raised a total of £912.00 by competing in the Great North Run on the 21st of September last year. The cheque was presented to Susan Little who's son Dean, aged 9, has WDS. Susan said, " We want to thank everyone for their help, and all those who sponsored them".

Gift Aid & Give As You Earn Schemes

As a small support group run completely by volunteers with no financial backing, there is a need to raise funds in order to hold our annual family fun days and cover the costs of things like the newsletters etc.

We have had some fantastic support from people donating money from sponsorships in the past and we would welcome anyone wishing to do so in the future.

Another way we can do it is by government-backed schemes such as Gift Aid and Give As You Earn.

Give As You Earn, the UK's largest and most successful payroll-giving scheme, means that any employee or pensioner paid under PAYE can donate to any charitable organisation in the UK.

Why Give As You Earn? Because giving direct from your pay is tax-free and causes like us will benefit from your regular support. What's more, from April 2004 the Government will be adding an extra 10% to your pledge.

For example: If you pledge, from April 1st 2004, £10 from your gross salary each month, it will only cost you £7.80 (depending on your tax bracket) but the charity will get £11.

If you would like further information please call the give as you earn help line on 01732 520019 or visit the website www.giveasyouearn.org or contact Jacqui Leech on 01376 348948 or by email on fundraising@wdssg.org.uk.

The Family Fund (Formerly The Joseph Rowntree Trust)

The Family Fund champions an inclusive society where families with severely disabled or seriously ill children have choices and the opportunity to enjoy ordinary life.

We help families of disabled and seriously ill children under the age of 16.

We give grants and information related to the care of the child.

The range of grants includes holidays, leisure, laundry equipment, driving lessons, and lots more.

The range of information we produce includes subjects such as benefits, holidays and transport.

To find out if we can help you, you can:

1. Apply On Line - www.familyfundtrust.org.uk
2. Phone us on 0845 130 45 42 - Our telephone staff are specially trained to help you with any questions you may have. You can call us to discuss your requirements. We have Minicom for people with a hearing impairment: 01904 658085. If you need an interpreter, call us on 0845 130 45 42 and tell us which language you speak. We will arrange for an interpreter.
3. Fill in our application form - Call us on 0845 130 45 42 and we will post a form to you. Or you can download a form from our web sit and post it to: Family Fund, PO Box 50, York YO1 9ZX

We also have information sheets available on a large selection of subjects. Please contact us for further information.

Address: Family Fund, PO Box 50, York, YO1 9ZX.

Tel: 08451 304542

Email: info@familyfund.org.uk

Website: www.familyfundtrust.org.uk

Special Abilities Ltd

Special Abilities Ltd has been set up to provide training programmes to parents/carers of a special needs person and to service providers, organisations and individuals with an interest in special needs issues.

They have a series of training courses available on the following subjects

The Medical Model

The Social Model of Disability

The Definition Of A Disabled Person

Stress and anger management training

Confidence and Assertiveness training

The main aim for all the above training is to try to get non-disabled people to understand the society, feel empathy, and hopefully change their way of thinking towards all people regardless of their disability.

For further information please contact Special Abilities Ltd.

Address: PO Box 360 Wakefield WF2 8WG

Tel: 01924 385977 or 07796 038291

Email: special-abilities-ltd@abilities.fsnet.co.uk

The Education Show London & Special Needs London

Dates: 30th September - 2nd October 2004

Venue: National Hall, Olympia, London.

Special Needs London

An exhibition well worth attending housing every resource for special educational needs ranging from school placements, computer software packages, Makaton products, books etc. to dietary supplements such as omega3 oils and Efalex.

For further information check out the website at <http://www.specialneeds london.co.uk/>



Research on Congenital Bilateral Perisylvian Syndrome

The laboratory of Dr. Christopher A. Walsh at Beth Israel Deaconess Medical Centre and Harvard Medical School in Boston, Massachusetts is searching for a gene that may be responsible for Congenital Bilateral Perisylvian Syndrome (CBPS). Discovering a gene involved will help us to understand the process of brain development. It may also allow the possibility of genetic testing for close family members.

Families choosing to participate would be asked to send a blood sample from the individual with CBPS as well as from each parent if possible. We would also request to review medical records and films from MRI or CT imaging. You do not need to travel to Boston to participate, and we pay for all costs involved in the research.

For more information about this study, or if you are interested in participating, please contact our genetic counsellors/study coordinators Adria Bodell, MS or Kira Apse, ScM at walshlab@bidmc.harvard.edu.

For more information about the Walsh Laboratory please visit www.walshlab.org.

The Challenging Behaviour Foundation

Is a charity that aims to provide an authoritative first point of reference for those involved with individuals that have learning disabilities and challenging behaviour.

Challenging behaviour blocks an individual's development. Addressing that behaviour can lead to a brighter future for the individual and their family. The CBF aims to be an easily accessible source of information and current developments within the field. The CBF provides and accesses support, advice and information in addition to raising awareness of challenging behaviour.

Feel free to contact us.

Address: The Challenging Behaviour Foundation, 32 Twydall Lane, Gillingham, Kent, ME8 6HX.

Tel/Fax: 01634 302207

Email: vivcooper@theCBF.freemove.co.uk

Website www.theCBF.org.uk

Useful Information

The Aidis Trust - A national charity that is able to provide hundreds of communication solutions each year.

Address: The Aidis Trust, 1 Albany Park, Cabot Lane, Poole, Dorset BH17 7BX

Tel: 01202 695244 Fax: 01202 695322

Email: info@aidis.org

Website: www.aidis.org

Communication Aids Project - CAP is funded by the DfES, and seeks to help pupils in England who have communication difficulties. It provides technology to access the curriculum and interact with others, and supports the transition to post-school provision.

Address; CAP, The CAP Administrator, BECTa, Milburn Hill Road, Science Park, Coventry, CV4 7JJ.

Tel: 02476 416994

Website: cap.becta.org.uk

Communications Forum - Brings together the UK organisations concerned with the needs of people with speech and language impairments.

Address: Communications Forum, Camelford House, 87-89 Albert Embankment, London, SE1 7TP.

Tel: 020 7582 9200 Fax:- 020 7582 9606

Email: cf@communicationsforum.co.uk

Website: www.communicationsforum.co.uk

Communication Matters - A UK national organisation of members concerned with the AAC needs of people with complex communication needs. Publishes a journal and holds conferences and study days.

Address: Communication Matters / ISAAC (UK) - 92 Windmill Road, Oxford OX3 7DR

Tel & Fax: 0845 456 8211

Email: admin@communicationmatters.org.uk

Website: www.communicationmatters.org.uk

Find a Voice – A Kent-based charity providing support to families, enablers and people with complex communication needs.

Address: Find a Voice, 49 Beaver Lane, Ashford, Kent. TN23 5NU.

Tel: 01233 640443

Email: joy@findavoice.org.uk

Website: www.findavoice.org.uk

The Sequal Trust - A charity offering assessment and fund-raising services for communication aids for children and adults with speech and/or movement and learning difficulties throughout the UK.

Address: The Sequal Trust, 3 Ploughman's Corner, Wharf Road, Ellesmere, Shrops, SY12 0EJ.

Tel/Fax: 01691 624222

Email: sequal@freenet.co.uk

Website: www.the-sequal-trust.org.uk

If you know of an organisation that another member may find of use, please share the information with us and we will put it in the next newsletter.

WORDS

Please remember that this newsletter is by our members for our members. If you would like to submit anything for our next issue please send it to our editor Graham Spencer, his details are below. We would gratefully receive short stories, personal insights, poems, funny stories or indeed anything that you might consider useful.

Generally we keep the articles as sent but sometimes it may be necessary to edit them slightly for various reasons.

The Editor and The Worster Drought Syndrome Support Group do not accept any responsibility for the views of contributors expressed in this newsletter.

The next issue of WORDS will be after the Family Fun Day, around the end of June.

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